



# What is Down Syndrome?

Down syndrome is a genetic condition that occurs in males and females of all racial and ethnic backgrounds. It causes different types of birth defects, as well as developmental disabilities. Down syndrome occurs in about 1 in 800 people.

## Michigan Resources & Support

### Down Syndrome Support Groups

[www.migeneticsconnection.org](http://www.migeneticsconnection.org)

click on "support group directory"

### Children's Special Health Care Services

Family Phone Line

Toll-free: 1-800-359-3722

E-mail: [ppp@michigan.gov](mailto:ppp@michigan.gov)

[www.michigan.gov/cshcs](http://www.michigan.gov/cshcs)

### Early On<sup>®</sup> Michigan

Toll-free: 1-800-EARLY ON

[www.1800earlyon.org](http://www.1800earlyon.org)

### Michigan Birth Defects Program

Nurse Follow-up Coordinator

Toll-free: 1-866-852-1247

E-mail: [BDRfollowup@michigan.gov](mailto:BDRfollowup@michigan.gov)

### Project PERFORM

[www.wash.k12.mi.us/perform/](http://www.wash.k12.mi.us/perform/)

### The Arc Michigan- Family Information Exchange

[www.arcmi.org/FIE.htm](http://www.arcmi.org/FIE.htm)

## National Resources & Support

### National Down Syndrome Congress

Toll-free: 1-800-232-6372

[www.ndscenter.org](http://www.ndscenter.org)

### National Down Syndrome Society

Toll-free: 1-800-221-4602

[www.ndss.org](http://www.ndss.org)

### Family Village

[www.familyvillage.wisc.edu](http://www.familyvillage.wisc.edu)

### Genetics Home Reference

[www.ghr.nlm.nih.gov/condition=downsyndrome](http://www.ghr.nlm.nih.gov/condition=downsyndrome)

### KidsHealth.org

[www.kidshealth.org/parent/medical/genetic/down\\_syndrome.html](http://www.kidshealth.org/parent/medical/genetic/down_syndrome.html)

### March of Dimes

[www.marchofdimes.com](http://www.marchofdimes.com)

click on Birth Defects

## How may Down syndrome affect my child?

**Learning:** There is wide variation in the mental abilities of children with Down syndrome. Most have developmental delays. They usually learn at a slower pace, but do not lose skills once they are acquired. They may also have trouble with judgment and reasoning. The degree of mental impairment is usually in the mild to moderate range.

**Behavior:** Emotional problems such as behavior issues or depression may occur beginning in childhood.

**Physical:** Common facial features include upward slanting eyes with epicanthal folds (skin over the inside

corner of the eye), a small mouth, and a flat nasal bridge. Children with Down syndrome are often shorter than average, and prone to extra weight gain. Babies may seem "floppy" due to low muscle tone (hypotonia).

**Medical:** About 1 in 2 children has a heart defect, which can range from minor to very serious. Other common health concerns include vision or hearing problems, thyroid disease, and unstable bones in the neck (atlantoaxial instability). Health problems such as seizures, diabetes, low resistance to infections, intestinal obstruction, and leukemia also affect some people with Down syndrome.

## How does Down syndrome occur?

Down syndrome is caused by an extra copy of the #21 chromosome. The child is usually the first and only family member affected, but sometimes there is a family history. In a few families, the extra chromosome is passed down from a parent. The chance of having a baby with Down syndrome increases with a woman's age. Genetic counseling is recommended for parents to learn more about the cause of Down syndrome in their family, and possible risks for other children or relatives.

## How is Down syndrome treated?

Down syndrome cannot be cured, but some symptoms can be treated. All children with Down syndrome should be checked for heart defects to find out if medication or surgery is needed. Infants and toddlers (birth to 3 years) should be connected with *Early On*<sup>®</sup> Michigan as soon as possible; while children over 3 years of age should be referred for special education services to address developmental concerns. Physical and occupational therapies may be helpful. Thyroid levels should be checked, and vision/hearing should be screened on a regular basis. Other treatments may be needed for health problems as they arise. Children with Down syndrome and their families benefit from having a primary care physician who helps to coordinate their care with medical specialists and other community-based services.

For more information, call Michigan's Genetics & Birth Defects Program toll-free at 1-866-852-1247 or e-mail [Genetics@michigan.gov](mailto:Genetics@michigan.gov)

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